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ABSTRACT

This manual, developed by the Families in Action Project, is intended to provide parents and other family members of children with emotional disorders some practical ideas and tools with which they can become effective partners with professionals in the policy-making process. The first section, "Understanding the Board Process," describes different types of policy-making bodies, their general roles and functions, and special issues that the parent (as a consumer representative) should consider. The second section, "Strategies for Effective Participation," looks at the various skills board members and advocates use to exert influence. Suggestions on improving communication skills, leading and participating in meetings, dealing with conflict, and getting one's message across are provided to help parents develop an effective, credible "style" of participation. The third section, "Organizing as Advocates," examines how family support and advocacy organizations can best influence the system, recruit and prepare members for policy-making roles, and avoid organizational "burnout" in trying to balance their responsibilities of mutual parent-to-parent support and system change efforts. The fourth section, "Resources for Decision-Making," provides a variety of information sheets, contacts for further information, and other materials to help parents obtain the background data needed to support proposals and ideas. (Contains 19 references.) (DB)

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Parents as Policy-Makers

A Handbook for Effective Participation

By: Richard W. Hunter

For the

Families In Action Project
Nancy M. Koroloff, Ph.D.,
Principal Investigator

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Richard W. Hunter
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INTRODUCTION

Generally speaking, when consumers set out to influence policy-making, they do so for a number of basic reasons:

- To ensure that services provided to the public are appropriate and accessible;
- To advocate for improvements in existing services or creation of new services; and
- To provide a clear and consistent voice for consumers in all aspects of the decision-making process.

For families of children with emotional disorders, the need to be partners in the development and oversight of services is a pressing one. Many families feel that too often services for their children and themselves are inadequate or unavailable. Too often, they experience a service system that is complicated, fragmented and impersonal, and that seems out of touch with the needs of the children and families it serves. Increasingly, parents (and professionals) are demanding that legislators, agency administrators and other decision-makers recognize the right of parents and other family members to sit down as partners at the policy-making table. Families are insisting that their expertise, skills and experiences are a vital part of all efforts to improve mental health services and they must be seen as peers in this process.

The purpose of this manual is to provide parents and other family members of children with emotional disorders some practical ideas and tools with which they can become effective partners with professionals in the policy-making process. It was developed to provide assistance and guidance to parents and other family members who are members of state or local agency boards, advisory committees or other formal decision-making bodies that are involved in shaping mental health services for children. This manual is not intended as a recipe for effective participation - there is no one way or preferred model - but rather, to provide practical information and tools that readers can use to help them maximize their participation and influence. In addition, it is intended to assist family support and advocacy organizations in their efforts to meet the increasing demand upon them to identify and recruit parents and other family members who can serve as consumer representatives on public boards and committees.

The manual is divided into four sections. The first section, *Understanding the Board Process*, describes different types of policy-making bodies, their general roles and functions, and discusses special issues that you, as a consumer representative, should consider. The second section, *Strategies for Effective Participation*, looks at the various skills board members and advocates use to exert influence. Suggestions on improving communication skills, leading and participating in meetings, dealing with conflict, and getting your message across are provided to help you develop an effective, credible "style" of participation. A third section, *Organizing as Advocates*, looks at how family support

and advocacy organizations can best influence the system, recruit and prepare members for policy-making roles, and avoid organizational "burnout" in trying to balance their responsibilities of mutual, parent-to-parent support and system change efforts. The fourth section, *Resources for Decision-Making*, provides a variety of information sheets, contacts for further information, and other materials that may help you obtain the kind of background data you need to support your proposals and ideas.

Finally, we urge you to put this manual in a loose leaf binder so that you can add additional materials you come across, include notes, reflections, personal action plans or other ideas and thoughts that you have as you help shape policy for children and families.

SECTION I:

UNDERSTANDING THE POLICY-MAKING PROCESS

What is Policy?

Formal policies are the written framework by which an agency or organization governs and operates its programs and services. Policies provide for the philosophy and practical basis on which decisions are made -- they provide direction to agency administrators and staff as to what kinds of services will be offered, how those services will be provided, and who will receive services. Usually, at least three types of policy that govern organizations can be identified:

The Mission Statement usually defines both the overall purpose and philosophy of the organization as well as its overall goals and objectives. The mission statement and accompanying goals and objectives represent the governing policy of the organization or agency.

A simple example of a mission statement might be: "This organization believes that every child is entitled to the most appropriate education that best meets that child's individual needs. Towards that end, this organization will provide parents with information, training and other forms of support necessary for them to be effective advocates for their child's education."

Administrative policies describe the various fiscal, physical plant, personnel and other overall standards by which the agency operates. These policies ensure that the administration of the agency is conducted in accordance with the overall mission and philosophy.

Operating policies specify the particular rules and procedures that are to be followed by agency staff to perform their duties. For example, in a mental health agency, these might specify how many clients are to be on each worker's caseload, number of sessions offered, or forms that must be completed.

Deciding Where You Want to Be

Policy-making boards and committees have various names and take on many different forms, each with differing functions, roles and levels of power in the decision-making process. The influence of a group will largely be dependent upon its mission, the level of legal authority (if any) of its decisions, and the awareness of its members as to their rights and responsibilities as participants. As a board or committee member, it is critical that you understand from the beginning (hopefully, before you join!) exactly what type of group

you are on, its overall purpose and powers, and your rights and responsibilities as a member.

Moreover, as you consider involvement on a board and committee it is important that you think about both the costs and benefits of involvement.

Some Benefits of Involvement

The opportunity to gain new skills and knowledge

The ability to make your voice and the voices of other families count

An opportunity to work in partnership with professionals and policy-makers

A forum to exert and affirm your expertise and competence as a parent/advocate

A chance to help change for the better the way things are done for not only your own child and family, but for other children and families as well

Some Costs of Involvement

Taking on additional responsibilities

More time apart from your family and child to attend meetings

Balancing your own needs and opinions with those of families you represent

Possible additional financial costs (e.g., child care, transportation, time off from job)

To help consider these factors, you may want to fill out the following self-inventory of your interests, needs and skills.

Self-Inventory for Involvement

- What particular issues or types of services am I most interested in? (for example: respite care, day treatment, special education)

- What boards or committees are most likely to deal with my interests? Who can steer me in the right direction?

- What do I hope to achieve from serving on a board or committee?

- What skills and knowledge do I want to gain from this experience?

- What skills and knowledge do I bring to a board or committee?

- How much time and energy do I have to work on a board or committee?

- What do I need to learn to be an effective member on a board or committee?

- Who (professionals, parents, parent organizations) is available to be a support to me in this work, and how?

Common Types of Policy-Making Bodies

In most states, private, non-profit (or not-for-profit) organizations are governed by a *board of directors*. Typically, this type of board has full legal responsibility (including potential legal liability) for the operation of the organization. Such boards normally are responsible for determining and monitoring the organization's programs and services, hiring an executive director and/or other staff to handle the day-to-day business of the organization, developing and overseeing program operation policies, procedures and rules (and seeing to their proper implementation), and assuring the funds of the organization are properly managed. In the mental health field, such organizations may be a public education and/or service organization (such as a local mental health association, private mental health clinic, statewide parent support organization, or parent training and information center). Sometimes, these organizations may receive public monies in the form of contracts or grants to provide services to children and families and must be accountable to the granting agency for proper use of the funds.

In public agencies, formal *regulatory boards* may be established by legislation or administrative rules. The extent and limits of their power may vary depending upon how specific the authority and funding of the boards has been designated in law or rule. Some regulatory boards, such as state licensing boards, may have broad authority to establish minimum standards of education and practice for a particular profession. On the other hand, they may have much less power to discipline professionals for violations of standards or to impose penalties. In the social service and mental health fields, such boards are typically composed of members of the particular profession, although some may have provisions for lay citizen membership.

More often than not, consumers will have the most impact on (and access to) public agencies and policies through participation on various *policy-making, advisory, planning boards*, councils and committees established by statute, administrative rule or choice by a particular agency. Once again, the extent and limits of power for these boards will vary widely. Some boards may have the authority to establish standards and policies that must be implemented by the affected agencies. Other boards may have the power to suggest or recommend policy changes to administrators, legislators or other decision-makers who then decide if they will adopt, modify or reject the recommendations. *Ad hoc committees* are often formed by a board, committee, or agency administrator to look at a particular issue and report back their findings and/or recommendations within a specific period of time

Planning, advisory and ad hoc boards and committees play a very important role in shaping policy and practices in many public agencies. They are made up of professionals, consumers and other citizens seen by agencies as offering special expertise, knowledge and skills. Agencies depend upon these people to provide direction and specific recommendations to administrators and lawmakers on how effective services are, what changes in existing services need to be made, what new services should be created, and (with your involvement) how responsive and accountable the agency is to those it serves.

Knowing Your Rights and Responsibilities

Being a member of a board or committee provides you the opportunity to express your opinions and to strongly advocate for programs and services you feel are important to families. As a consumer, you bring a type of expertise that most professionals do not have: the experiences of a parent who has the intimate, 24 hour a day knowledge of what caring for a child with an emotional disorder means, what services are most helpful to your child and family (and the families of children you represent), what barriers stand in the way of truly helpful services, and what unmet needs agencies must address.

As a board or committee member, you have the right to expect that your opinions and proposals for action are listened to, respected and equally considered by other members. As a member, you have the right to make motions, enter into discussions, cast your vote, and receive the same types or amount of any compensation available to other members for their time and work In short, you are entitled to full participation and membership.

To exercise these rights, you need to be fully informed about the history of the group you are joining (or currently serving on), what its purpose and powers are, and how the group operates and makes decisions. Here are some general questions you should consider asking:

- ⇒ What agency or body established this board?
- ⇒ What are the board's specific goals and purposes?
- ⇒ Are there written bylaws or purposes?
- ⇒ In what capacity does the board operate? Is it
  - advisory?
  - regulatory?
  - policy-making?
- ⇒ Who does this board report to?
- ⇒ Do you have a clear understanding of what your duties are as a member?

Being a member of a board or committee also means that you accept the responsibilities and obligations that come with the opportunity to influence change. As a board member, you have the responsibility of working with other members to fulfill the mission and duties of the board.

Responsibilities of an Effective Board Member

- To be fully informed about the issues the board is dealing with;
- To work within the rules agreed to by the board;
- To be open to considering opposing opinions and viewpoints;
- To attend meetings regularly and participate in assigned work;
- To accurately reflect the views of the constituency you represent;
- To be willing to compromise and negotiate when appropriate;
- To treat other board members with respect and equal consideration; and
- To express your views as persuasively and reasonably as possible.

An effective board member is one who can work cooperatively with other members, build working relationships with others, get his or her point across in a way that is understandable to and respectful of others, and share equally in the work of the group.

As a consumer representative, you also have obligations to the parents and families you represent. To fulfill these responsibilities, you want to:

- educate other board members on the needs and interests of families;
- inform and seek advice from families or their organizations concerning issues of interest to them;
- conduct your business on the board in a way that establishes your credibility;
- know when to negotiate and compromise;
- encourage other parents to come to meetings or join the board;
- advocate on behalf of underserved and culturally diverse groups;
- encourage the board's accountability to families for its decisions; and
- fully understand the implications for families of board decisions and the positions you personally take.

Everyone wants to feel accepted as a member of a group. Being comfortable working on a board or committee doesn't mean you have to be "co-opted" or shed your role as a consumer advocate and representative. By being clear about what your goals and objectives are, and by seeking constant advice and support from other parents and parent organizations, you can help avoid the feelings of intimidation and incompetence that can arise when in a room full of professionals or when the discussion turns to highly technical subjects.

Learn How the Board or Committee Operates

Every board tends to have its own unique way of operating, depending upon its history, purpose and personal styles of the members. Some boards may be very formal, following strict procedural rules for discussion and decision-making. This can be helpful when the

board is examining complex or controversial issues that require careful attention to detail or when the board meeting is open to the public and must ensure that all important agenda items are addressed. Most advisory boards and committees tend to function more informally, and it is assumed that the common sense of members to focus their discussion and heed time limits will be respected.

Observe the decision-making process

By observing how your group operates, you can anticipate what kinds of skills you will need to be effective. For example, if decisions are made by a vote of the majority and you are the only consumer representative on the board, you will know that it is important to be well prepared and articulate in presenting your views. If the group operates more from a consensus style of decision-making, your abilities to negotiate and compromise will be very important. You will also need to find out who your potential allies on the board are and work with them to get your point across. You might decide that getting other consumers to attend as observers or to offer public testimony will help persuade other board members to your side

Find out if minority positions are included in minutes of decisions. If you are outvoted on a particular position, ask that your minority opinion be placed in the record. Also, make sure that the minutes record all the factors that were discussed in coming to a decision, what minority views were expressed and for what reasons they were rejected. It is not uncommon that decisions are re-visited at a later date and a record of past discussions can be invaluable in this process.

Obtain written information and records

Most boards and committees keep records of their discussions and decisions. Study the minutes, reports or other written accounts of the board's activities. If you are new to a board, reviewing these records will give you a sense of the history of the board, how members have stood on similar or the same issues in the past, and what gaps in information or misunderstandings of the issue may be operating. In addition to the formal minutes of a meeting it is important that you keep your own notes of what went on, to keep track of different points of view, and to prioritize and evaluate your own positions.

Get to know and learn from other board members

Examine who is on the board. If the board is large, obviously there will be more opinions and interests competing with yours. If the board is small, say five or six, the weight of your opinion and vote, even if in the minority, may be very important. Often, members are chosen because of particular skills or knowledge that they have. Find out what areas members have expertise in and work with them to fill in gaps in your knowledge. For example, if you feel lost when budgets are discussed, get together before or after a meeting with the person who understands finances and ask them to help you understand the issues.

Find out if there are other parents or family members on the board. Your role may be different depending on whether you are the only consumer representative or if there are others with whom you can work and strategize. If you are the only consumer, consider raising the issue of adding more consumer representatives on the board. Look for the extent of cultural diversity within the board; does the board have family members who represent the cultural makeup of your community? Given the diversity of families in any community, you have a strong argument that one parent cannot be expected to truly represent this diversity.

A Checklist for Understanding Board Operations

- How does the board set its business agenda?
- What procedures does the board use to discuss agenda items?
- What is the decision-making procedure used?
- What kinds of records does the board keep?
- What are the different sub-committees and which would you like to work on?
- How many members are on the board and what constituencies do they represent?
- What expertise do different members (including yourself) have?
- How many parents or family members are there?
- Are culturally diverse families and underserved populations represented?

A Checklist for Gathering Needed Information

Do I have copies of:

- board bylaws, rules, mission statement or other statements of purposes?
- minutes of previous meetings?
- any annual reports or other documents issued by the group?
- financial reports or budget information on the board?
- the names of the board members and the constituencies they represent?
- organizational charts of the board, agency or body it reports to?

- Have I asked for or received a formal orientation to my role as a board member?
- Who do I need to meet with for more information (for example: the chairperson, other members with particular expertise)?
- Do I know what the demographics of the community are and who is not represented on this group?

NOTES:

SECTION II:

STRATEGIES FOR EFFECTIVE PARTICIPATION

This section addresses how to effectively participate as a member of a policy-making board or committee. Effective participation requires that you as a member of the board understand the process of a meeting, how to positively contribute to discussion, and how to influence others. There are a number of tools that you can use to increase your communication skills, learn to negotiate and deal with conflict, and take a leadership role in advocating for the needs of families of children with emotional disorders. Applying these skills and tools can:

- Help the group (and you) use time more efficiently and accomplish something;
- Assist you to better understand the issues important to families; and
- Help you persuade others on the board as to the value of your ideas and proposals.

Understanding Groups and Group Process

When people work together in groups they often form their own unique processes of communicating and decision-making - in many ways - their own "culture." For example, the culture of a parent support group may have few rules and encourage strong expressions of feeling, while an agency advisory board may have very formal rules and procedures for discussion. By understanding this culture - these shared experiences (both good and bad), interpersonal relationships, and open and hidden forms of communication - you can learn how this group deals with both the **content** (what is being discussed) and **process** (how it is being discussed) of interactions. At the same time, you can use this knowledge to both effectively push forward your ideas, as well as help the group to form better methods of communicating and making decisions.

Most of the time, when we first join a board or committee, we have an "ideal" of how we see that group working. We imagine that the group will have a clear purpose, share common goals, and work cooperatively towards solutions. We look forward to a meeting in which views and opinions are equally shared and considered; where an agenda is clear and logical, has reasonable time limits, and problems are identified, analyzed, and solved in an atmosphere of reason and calm.

While the above description of group process is desirable and possible, usually groups do not function as smoothly and logically as you would like or expect. Often, the reality is that other people on the group may have characteristics that you find difficult to deal with. There may be members who dominate the discussion, interrupt others while they are

talking, or act disinterested when opposing views are being expressed. You may feel that other members of the board treat you and other consumer representatives as tokens, or talk down to you because they think you can not understand the complexity of the issues being discussed, or, the group may talk the whole meeting and still come to no decisions.

If you have experienced some of these feelings, you are not alone. Most groups are not as efficient and responsive as they should be, and most of us have not been trained in skills for working in groups. However, there are some tips and strategies that you can use to increase your own effectiveness. These include:

Working with the Meeting Agenda

Communicating Effectively

Learning how to Negotiate and Deal with Conflict

Finding and Working with Your Allies

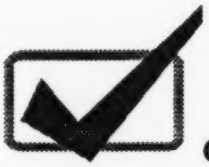
Working with the Agenda

Most meetings follow an agenda. A typical agenda is drawn up by the chair based on what old business remains from the last meeting and new items that have come from members, the agency or organization the board serves, or outside requests. Most often, the sequence of the agenda items will determine which ones get the most attention. In other words, the further up on the list an item is, the more likely it will get the most attention from the board. The farther down the list, the less likely it is that time will be available for its full consideration or that time will run out and it will be postponed until a later meeting.

To effectively use the agenda, be sure that the agenda is distributed to you and other members **before** the meeting so you can have time to review it. If agendas are not mailed out in advance, be persistent in your request that this be done. This will not always be easy, but it is important to keep trying. If mailing out agendas isn't possible, consider calling the chair a couple of days in advance and ask him or her what items are to be discussed at the meeting.

Once you have the agenda:

- Study the agenda as you consider the following:
  - What is each item about and who proposed it?
  - Why was the item proposed (you can always call the person and discuss their reasons)?
  - What questions do you have; what additional information do you want?
  - What are your initial reactions concerning the item?
- Identify items on the agenda you think should receive high priority
- Identify agenda items not on the list that you think should be included
  - Call the chair and request they be added or be prepared to offer them at the beginning of the meeting. If this doesn't work, at the end of the meeting, request that your items be placed on the agenda for the next meeting.
- Try to have your agenda items placed on the top of the agenda if you want them to get the most attention from other board members



Communicating Effectively

Communication is the essential ingredient for success. Your effectiveness as a board member depends on your ability to communicate well with other members and understand the impact of differing communication styles - this may be particularly true when the board consists of members from different socio-economic backgrounds or culturally diverse groups. The ability to communicate is a skill. And like any skill, effective communication is best acquired through practice and learning from your mistakes. Effective communication not only involves the ability to persuade others to your point of view, but the ability to listen to others, ask questions and clarify, and adapt or change your own views when it is indicated.

Ask Questions and Join in the Discussion

Questions are the cornerstone of good communication. Two-way communication doesn't happen when two people trade statements with each other - it happens when we ASK QUESTIONS in order to understand what the other person means, what they want, and why it is important to them or those they represent.

Suppose your committee is discussing the merits of respite care services to families as part of a local mental health program. Different kinds of questions can be used to obtain information, facts, opinions, and clarification, to invite others to join the discussion, and to help a group reach decisions:[1]

Informational Questions	When will respite care be given to families? How will these services fit with the special needs of each child?
Factual Questions	How many families will be served? How much will families have to pay for each hour of respite care?

[1] Adapted from Cohen, R. (1982). Representing the consumer: Strategies for effective board participation. Washington, D.C.: American Association of Retired Persons.

Obtaining Opinions	Do you think there are enough trained providers to serve this need? Do you believe the service should be given in the home or somewhere else? What do you think of having parents involved in training?
Clarifying Questions	Is it correct that you project that the costs of respite will be offset by the number of children kept out of foster-care? Could you go over your figures again so we understand?
Inviting Questions	Mr. Williams, how could your agency help this service succeed? Dr. Frank, what are your opinions on the best training methods for providers?
Decision Questions	Have we discussed this long enough to agree that this service is needed? Is it correct that the only other decision to make is what kind of training to give the providers?

Listen Carefully to What Others Have to Say

Listening is much more difficult than we realize. Many times, instead of really listening to what a person is saying, we are thinking about what we just said, or what we plan to say in response to the other person. When that happens, we may misunderstand what the other is saying, ignore or not hear important facts or information they are sharing, and give them the general impression that we do not care about their opinions. Just as you want people to listen carefully to what you say, it is your obligation to treat them with the same respect and attention you expect.

When Listening, DO

- Concentrate on what the speaker is saying
- Take notes of the main points
- Be aware of the possible impact of cultural differences on how you understand or react to the speaker
- Mentally note the points you agree with as well as those with which you disagree
- Be open to opposing views and consider their reasons
- Think about questions that will clarify what you do not understand

AVOID

- Interrupting
- Doing other work, reading papers, talking to others or other actions that will distract you (and the speaker)
- Jumping to conclusions
- Discounting or ignoring what you do not agree with

Making Your Case

Presenting ideas and arguments convincingly is a matter of preparation, anticipation, organization and practice. It may also involve following up with members after your presentation to understand their questions, thanking those who supported you, or meeting with those who disagree with you to better understand their position.

As an example, let's use the issue of respite care services again. Suppose the families in your community want a state agency (whose advisory committee you are a member of)

to provide respite care to them. You would like the committee to make a recommendation to the agency that respite services are necessary and should be a part of their program.

Where do I start?

- **Collect information and evidence** about the issue and why it is important
  - descriptions of respite care models and services
  - statistics from the agency on how many clients it may affect
  - interviews with families about why they think it is important and what it has done for them in the past
  - interviews with staff to see how it would help their work with families
  - information from other agencies or programs that provide respite services (for example: contacting the local Developmental Disabilities Council to find out why they developed programs for their clients, what it has accomplished, problems they have had, and program costs)
  - letters from parents documenting the need
  - information on the consequences of not having respite care (such as increased family problems, more restrictive care, or greater utilization of out-of-home care and increased agency costs)

What else can I prepare?

- **Document your case and consider alternative solutions**
  - information on how much respite services might cost; and
  - examples from other states to show it is a national concern (call parent organizations in other states, or the Portland Research and Training Center to gather facts and figures).
  - Are there other agencies that could or already provide the service?
  - Are there volunteer organizations that could be involved?
  - Are there grants the agency could apply for to pay for the services?

Could other solutions work better than my proposal?

- **Consider the merits of other alternative solutions:**
  - Could another agency do the job better?
  - Can the service be provided at a reasonable cost?
  - Should we try a model program first to see if it works?
  - Will respite services help ease the problems families see as a priority?

- **What other factors should I consider?**
  - Are there licensing requirements for respite providers?
  - Are there resources to train providers?
  - Where could respite be provided (in home, a center, etc.)?

What next?

- **Prepare my case**
  - organize your information into a concise, factual and objective presentation. In your presentation, briefly describe why respite care is an issue and a pressing need (the history), what the different options are for providing it, and which solution you support and the reasons why. If helpful, create some handouts that outline your presentation or provide background facts you will not have time to fully cover.
  - go over your proposal with a friend, other parents, or supporting board members to get their reactions and suggestions.
  - practice your presentation so that you are comfortable with the material, to make sure the presentation is not too long, and to get feedback from friends on its clarity.

The above steps are general guidelines for preparing an organized and persuasive presentation. Some issues may not take as much preparation or require as much background research. Other issues may be so complex that it will take more than one meeting to fully examine the issue, and may require you to find additional information or arguments to strengthen your proposal. In either case, your ability to present in a manner that demonstrates your concern, attention to the important issues, openness to alternative solutions, and reasonableness will win you and your proposal respect and credibility.

Regardless of how simple or complex the proposal, some additional suggestions to consider when preparing or giving a presentation that will increase your persuasiveness are described below.

Anticipate Your Audience. As you prepare to make a proposal or enter into a discussion during a meeting, take a few moments to consider the interests and characteristics of your audience. Like you, every member of a board has particular interests or points of view that are personal and that represent the views of those they represent. Think ahead about how people in the group will react to your viewpoint and how it will challenge or support their positions. By anticipating possible objections,

questions, or areas of agreement, and including these factors in your presentation, you are less likely to unintentionally offend someone else or create unnecessary conflict. By anticipating their response, you can also try to find areas of agreement to emphasize as you present.

For example, you know that the representative from the child welfare agency believes that respite care is important, but it is something parents should find themselves and that agencies should not provide. In making your presentation, you can stress the agreement on the need for respite and include in your discussion of options, the advantages and disadvantages of volunteer programs versus funded respite programs. By acknowledging this agency representative's concerns ahead of time, and incorporating a description and evaluation of his or her probable suggestions among your list of solutions, you are more likely to hold his or her interest and positive participation in the discussion.

Consider Your Language and Style of Presentation. Something that seems perfectly clear to you may have an entirely different meaning (or be incomprehensible) to the person to whom you are talking. For example, when you talk about the need for family support services, you may be thinking of respite care, transportation assistance, or other concrete services to families. However, another member of the board may think that "family support" means family therapy programs.

When you are presenting, make sure the language and terms you use are commonly understood by the rest of the board or committee. Avoid using technical jargon or unusual terms that others may not have heard before. Likewise, when others use technical language or terms that are unclear, ask questions about what they mean and phrase it in your own words to make sure there is no confusion: "So, when you use the term 'the cost of service per unit', you mean all the expenses, like supplies, salaries, and so forth that are added up for each client? Is that correct?"

Often, other people have had different experiences than you. As a result, they may place a meaning different than what you intended based not only on your words, but also upon your gestures or appearance. The way you dress, carry yourself and interact with others will affect how you (and your ideas) are accepted by other group members. This does not mean that you have to act like someone you are not, but you should be aware that how you act or carry yourself might be a positive or negative factor in your presentation.

Watch the behavior of group members for cues on how they are reacting to your discussion. If members are restless, shifting their bodies a lot, or talking to others, it may be a sign that you are losing their attention (or that the meeting has been going on too long and people are tired). Gain their attention or clarify the situation by asking questions. If people are simply tired, it may be better to suggest that your item be continued as the first item at the next meeting. While it may delay a decision, waiting for another meeting may mean that you will get the full attention and consideration of the group.

If silence occurs, check your own emotional reaction to it. Does the silence feel comfortable or uncomfortable? Does it feel like people are listening intensely, or do people appear bored? If the topic you are discussing is emotional or controversial, silence may be an indication that people are uncomfortable with the topic, or people may feel too self-conscious to speak up on the topic. Once again, asking clarifying questions may help you gauge how group members are feeling.

Take note of people's eye contact with you. If people are watching you while you are talking, it usually is a sign that they are comfortable with you and are interested in what you have to say. Recognize this interest by keeping eye contact with your audience. If people avoid looking at you or at each other it may be a signal that they are uncomfortable or disagree with each other.

Watch people's physical posture. When people are wanting to ask a question or say something they often lean forward or shift their position. It also can be a sign that they are very interested in what you are saying. Similarly, observing the posture of members can give you an idea about how relaxed or tense they are.

TIPS FOR EFFECTIVE COMMUNICATION

- **Be a role model**. Your style and behavior can set the tone for a discussion. If you are speaking, members of a group will often follow your example. If you show that you are relaxed and comfortable with the topic, it is likely that the others will follow suit.

- **List your main points**. Listing the main points you plan to make in your discussion or presentation will help listeners focus their attention. It will also help you to organize your thoughts and stay on track.

- **Write it down**. Using a flip chart or a blackboard to emphasize your main points is another way of helping the group to stay focused and attentive to your ideas. Referring to handouts is another effective method, but keep them brief and few in number. Otherwise, people may spend their time reading the handouts but not listening to what you are saying!

- **Use examples** that have personal meaning for group members. When subjects are too abstract or removed from people's immediate experiences, they tend to drift away from the subject or fail to see the importance of what you are saying.

- **Anticipate** the reactions of the audience. Think ahead about how the group or individual members will feel about your proposals. If you can identify possible objections or questions, you can include this information in your presentation.

- **Use humor** to help relieve tension or change negative emotions. Be willing to laugh at yourself.

- **Trust your feelings** about how the group is reacting. Ask questions to check this out if necessary.

Making Your Case: A Checklist

1. *Collect information and evidence*
2. *Document your case*
3. *Consider alternative solutions or approaches*
4. *Evaluate the merits of all possible approaches*
5. *Anticipate your audience*
6. *Prepare your presentation*
7. *Practice and revise where necessary*

Learning how to Negotiate and Deal with Conflict

An effective advocate or consumer representative recognizes that change is a long-term endeavor and that answers to problems are often complex, can change over time, and are usually the result of compromise and negotiation. Few policies are adopted or changed without disagreement or conflict between group members. Competing interests and viewpoints make some level of conflict inevitable in most situations, and compromise positions that achieve a balance between these interests is sometimes the most desirable outcome to seek.

Negotiation does not mean taking a back seat to another position or viewpoint. In fact, incorporating the strengths of various positions can result in a much better decision or policy than any one proposal alone. As a parent representative, your interest is in protecting the rights and needs of family members, and encouraging others on the board to adopt policies and make program decisions that will better serve families. How effective you are as a negotiator and your ability to deal constructively with conflict will, to a large degree, determine your ultimate success. While there are times when you will decide that an issue is so important that a compromise cannot be made (and if that is the case, stick to your principles if you have thoroughly thought your position out), more often than not, most issues can be better understood and solved by incorporating differing views and considering alternative solutions.

While there are no particular "rules" to effective negotiation, some useful approaches to negotiating and making use of conflict are described below.

- **Identify your similarities and acknowledge differences.**

Try to identify those areas where you and those of opposing viewpoints agree. For example, "We all share a desire to improve the lives of children with emotional disorders and their families," or "It is clear that we agree that some form of respite care is important for families." By pointing out the common ground that all members share, you can help create an atmosphere of shared purpose.

Acknowledge areas where real differences occur. Avoiding conflict or differences will not help solve the problem, and will usually result in confusion, delay, or a feeling of hopelessness in coming to a decision. Lay out the differences fairly and develop a mutually agreed upon process to examine each area of difference.

- **Separate out personal feelings from the issues.**

Many times, open debate over the issues takes a back seat to personal antagonisms or attacks. Try to put aside your own personal feelings about the person and concentrate on the substance of what you are trying to accomplish. Be aware of how your personal biases can interfere with your goals. For example, you may not like the agency that another member represents, but you might discover that he or she is personally supportive of your position. Do not let the interest that the person represents cloud your understanding of what they are saying. Or, consider if an angry tone in your voice is being heard by the other person instead of the legitimate points you are making.

Point out to others when you feel that they are misunderstanding you or letting their emotions take control. Remind them of your common goals and your desire to work with them towards a mutually agreeable solution. Be persistent in your attempts to work reasonably with them and maintain an attitude that shows you are confident and optimistic.

- **Encourage Questions.**

Once again, clear communication is critical in negotiation. Make sure everyone understands the issues, words and proposals being discussed. One effective method is to occasionally summarize what has been discussed and ask if any additional clarification is needed.

Be aware of questions or comments that divert the discussion. This may be the result of confusion, or a deliberate attempt to stop progress. When confusion is the problem, restate the issue and use clarifying questions. When the purpose of the question or statement appears to be a diversion, politely point out that the statement is not pertinent to the subject being discussed and try to draw them back to the issues. For example, "I understand that you are concerned about funding respite care, but right now we are discussing whether respite is a needed service for families. How do you feel respite care could benefit families?"

- **Take a Break.**

When a discussion becomes too tense or highly charged with emotion, consider taking a break so members can relax and re-focus their thoughts. Taking a short break can allow people a chance to calm down, reflect upon the discussion, and think of new ways of solving the problem at hand. Use this time to reorganize your thoughts, think of new ways of communicating, or to socialize with other members to reduce tension.

- **Maintain an open attitude.**

Remember that members with opposing views may have alternative ideas or solutions that might improve upon or be more effective than yours. Listen carefully to their positions, facts and opinions. It is an unusual advocate who can anticipate all the possible problems

or pitfalls with their proposal. Remember that collective thinking and pooling of expertise almost always improves one person's idea or proposal.

- **Compromise on smaller issues that get in the way of the main objective.**

Look for opportunities where you can compromise without sacrificing your overall goals and objectives. Solving smaller problems will increase the group's confidence and promote an atmosphere of optimism and encouragement. Or, consider the tactic of agreeing first as a group about the main points of the proposal, acknowledging that there are disagreements over how to implement the plan or that there is a need to "fine tune" the proposal. If everyone fundamentally agrees with the overall proposal, they are likely to work cooperatively towards solving finer details.

- **Stand firm when you are confident of your facts.**

There are times when your position is clear and the facts are on your side. Be persistent and firm in your approach. Remember, you too are an expert on families and their needs, and you do not need to be intimidated by technical language, positions of authority or academic degrees. Sometimes a firm and solid position, backed up with facts is the most persuasive argument for accepting your proposal.

Find and Work With Your Allies

Take the time to socialize and get to know other members of the board or committee outside of meetings. Working relationships can only be improved when members know each other, share their personal experiences, and can work in an atmosphere of personal trust and comfort. Seek out the advice and opinions of other members when you are developing a proposal or position. This will involve them early in the process and may increase their interest in the importance of your issues. They also may have technical information you need or can steer you to persons or agencies that can provide you with needed facts and figures.

Rely on your friends, family and other families that your represent. Remember that you serve as their representative and they are your source of support and strength. Keep them fully informed of what the committee or board is working on -- ask their opinions, have them review and comment on written documents or reports, and discuss your problems working on the committee with them. If it helps, ask them to sit in as guests during the meeting as a source of moral support. If appropriate, arrange for families to attend the meeting and provide formal or informal testimony about the subject being discussed. If you are a member of a parent support or advocacy organization, work closely with your leadership to inform them of the issues and consult with them on how to effectively promote your interests. Remember, there is strength in numbers!

NOTES:

SECTION III:

ORGANIZING AS ADVOCATES

As legislation and funding requirements for state and local mental health, education and social service agencies have increasingly mandated the involvement of consumer representatives, parent support and advocacy organizations are often approached to provide representatives to serve on advisory and other decision-making boards. While this is a welcome and hard-fought-for change, it has also added to the responsibilities of parent organizations.

Finding family members who have the time, energy and inclination for getting involved as board members can sometimes be difficult. Often, parents may feel intimidated by the prospect of matching the meeting skills of professionals, of making public presentations, or taking on the responsibilities of representing families. Many family support and advocacy organization leaders/members are not sure which boards or committees are most important to serve on or are worth the time and energy of their members.

This section is intended to provide some suggestions to family support and advocacy organizations on ways to **create a strategic plan** for policy-making involvement, **recruit members** to serve on boards and committees, and effectively use the **influence** they have on the decision-making process.

Creating a Strategic Plan

Balancing the support needs of members with the need to influence system changes is a constant challenge for support and advocacy organizations. In the pressure of providing supportive help to families as well as maintaining the organization, it is not unusual for the leadership of parent organizations (often two or three parents) to also take on the primary responsibility of representing the organization and consumers on various state, local or even federal boards and committees. While these leaders often have the skills to be effective members, many also feel the burden of these additional responsibilities, and become "burned out" or over-committed.

At the same time, the process for deciding which boards and committees to target for organizational energy and time may be done in a haphazard or unplanned way. The members of organizations may find themselves with representatives on an overwhelming number of committees and boards with little sense of whether their time and effort serving

on them is worth the results. Other organizations may just be starting to consider becoming formally involved in policy-making and members are unsure where they should concentrate their work.

One potential solution to these problems is the creation by the organization of a strategic plan. Creating a strategic plan can provide the organization with both a process for deciding what issues and agencies they want to target as well as an organized plan of how they will proceed, who will be involved, how they will recruit members to serve on boards, what ways they will support their representatives, and a method for evaluating their effectiveness.

Essential Elements of a Strategic Plan for Involvement

- A prioritized identification of the policies or services you want to influence or change;
- Identification of the agencies, boards, and committees that make decisions about your priorities;
- An inventory of the interests and skills of your membership for serving on policy-making bodies;
- A plan of recruitment for organization members to serve on policy-making bodies, including members who are culturally diverse or from underserved populations;
- A process to support representatives on boards and committees; and
- A timely method for evaluating and revising your efforts.

Identifying the Policies or Services to Influence

This is the starting point for any organized change effort. It is important to work collectively with the membership of your organization to identify the major areas of policy change or service development that you want to see in your community and to prioritize where you will concentrate your efforts. Here are some possible ways you can involve your membership in this effort:

1. **Hold a general meeting and brainstorm with members**. Generate a list of all the suggestions by the group. You may want to use flip-charts and categorize suggestions under headings such as "Policy changes," "New Services" or "Changes in Services." Or, you may want to put suggestions under service system categories such as: "Special Education,, "Mental Health," or "Social Services."

2. **In a meeting of your organization's board of directors or leadership**, generate a preliminary list as above and then distribute this to your membership for their comments and additions. This couid be done through a mailing, a general meeting, individually or in small groups depending upon the size and resources of your organization.

3. **Meet with selected groups of your membership to generate ideas**. If you are a statewide organization this could be done, for example, with local support group leaders. Brainstorm with members who represent the diversity of your membership, not just those who are already serving on policy-making bodies.

4. **Consider the merits of involving supportive professionals** that you respect and trust in this process. They may be able to provide you with valuable "inside" information on the political implications of your choices, identify policy and program areas you may not be aware of, and current agency and system internal reform efforts or proposals.

After (or while) you generate the list of change options, **prioritize** your list to the three or four major policy or service areas that you want to influence. If you fail to prioritize, the odds are that your brainstorming efforts will leave you with a bewildering number of options and you will be overwhelmed trying to achieve all the changes you have identified. If your organization is large, it will probably make sense to have your board of directors or leadership prioritize the options. If your organization is small, try to reach consensus among the membership on top priorities. Keep in mind that as your work unfolds, some of your priorities may change, be impossible to tackle at this time, or be accomplished quicker than you expected and that you can always revisit your decisions.

Prioritizing Your Change Efforts - Questions to Consider

- **Which policies most effect (positive and negative) our families?**
- **What are our most immediate needs and concerns?**
- **Do we want to concentrate on one or more system, policy or program changes?**
- **Considering our time, numbers and energies, how many boards can we really serve on?**
- **Which boards and committees have the most decision-making power or influence?**

Identify the boards, committees or other decision-making bodies that influence your priorities. As you prioritize your change efforts, identify the boards and committees that make decisions on policies and programs that shape your issues of concern. Keep in mind that often a number of boards may deal with the same issue across agencies or systems. For example, if developing or improving respite services is a major goal of your group, keep in mind that these services may be offered by education agencies, mental health agencies, social service agencies, or others. Each agency may have their own policy-making board that oversees these separate programs. If this is the case, you may want to concentrate on one or two agencies, or ensure that you have representation on all of the boards. Or, you may want to do some research and find out if there is an overall coordinating or planning council at the state or community level that influences all of the different programs. In that case, you may want to concentrate your efforts there.

If you do not know what boards or committees oversee your areas of interest, ask questions. The most direct method is to contact the administrator of the agency or program and ask him or her. You may also ask supportive professionals which committees deal with your issues and which ones are the most powerful or influential. Ask your membership as well - you probably have members already serving on committees or who know what boards or committees affect your areas of interest.

Identifying and Evaluating Policy-Making Bodies

- Seek suggestions from your membership
- Talk to supportive professionals
- Meet with program and agency administrators
- Contact other consumer groups for suggestions and experiences
- Check local newspaper listings for public board and committee meetings
- Obtain copies of board by-laws and mission statements
- Review their actual decision-making power or influence

Find out if the boards and committees you have identified have or allow for consumer representatives. If they do, have individual members of your organization formally apply for the position or request as an organization that one or more representative(s) be appointed to serve. Approach committee members and ask them to nominate a member or members from your organization to sit on the board, or make a motion that the board recruit consumer representatives, offering your organization as an immediate and appropriate source.

Some policy-making, planning and advisory boards are restricted by administrative rules or legislation as to who can serve on them. You may find that these boards are required to have consumer representation but they have not been filled - offer your services immediately! Or, you may find that consumer representation has been limited to a particular group, for example, adult consumers who have chronic mental illness. Or, as is sometimes the case, the membership is restricted to agency representatives or appointments by the legislature, governor or agency administrator.

If consumer representation is not restricted; yet is not being provided, approach the board chair and members informally and formally to request representation for consumers. Provide them with a rationale for consumer representation: point out the benefits to planning that consumers provide, extend the willingness of your organization to provide representation, identify other agencies or systems that include consumers and the positive impact that has had, and stress the positive benefits of family and professional collaboration in making their work easier and program success more likely.

If consumer representation is not allowed because of administrative rules or legislation, you will have to decide if the effort to change those rules or laws is worth the potential benefit of representation. Or, you may decide that developing informal relationships with board members as a way of educating them on consumer needs and issues is a better strategy for now.

Recruiting and Supporting Members for Participation

The ability of your organization to influence the policies and services you have prioritized is directly related to the number of family members you have willing to serve on decision-making bodies and the level of support and direction you can provide them. Consumers serve on boards because they believe their work will have a direct impact on their own family and other families in similar situations. They also should rightfully expect that the members of the organization they represent appreciate their work, support their efforts, and are willing to provide them with consultation and concrete assistance. In addition, consumers should expect that the organization they represent has ensured that members

participating on boards should represent the economic, geographic and ethnic diversity of its membership.

As part of your strategic plan you should develop a process to recruit members to serve on boards and methods to provide them consultation and involve their activities in the overall goals of the organization. In developing a recruitment plan, consider the following factors and issues:

Develop an inventory of member interests, willingness to participate, and support needs.

Contact the individual members of your organization to explore with them their interest in being on policy-making boards. Review your strategic plan with them and what role they might play in it. Find out what issues and boards or committees may fit their individual concerns, time limitations for participation, resources they would need (e.g., training, mentoring, help with transportation or respite, etc.) to actively participate, and willingness to work closely with you in sharing information and developing strategies to influence particular board or committee policy decisions.

Consider the various levels of participation that individuals feel most comfortable with. Some family members may be ready to serve on a board with minimal support, others may want to observe a board or another member in action as a board participant. Still others may be more effective as a "support buddy" to another parent serving on a board, helping them plan their work, listening to their concerns, or sitting in as a guest at meetings to lend their physical and emotional support to the board member.

Identify the number of members you will need to serve on policy-making bodies.

As you prioritize your list of boards and committees, realistically assess how many your organization can actually serve on, given your membership size and their (and your) time and energy constraints. While some members may be able to serve on more than one committee, it is probably unrealistic to expect that of most family members. As you develop your inventory, you will probably get a good idea of how many people are immediately available for participation as well as an idea of future availability. At this point, you may want to re-visit your overall strategic plan and re-prioritize your efforts.

Develop short term and long range goals for participation.

Recognize that recruiting participants in policy-making is an unfolding process that builds and grows upon experience, mistakes, and changing priorities of your organization. Your first short term goal is to identify a group of committed members currently serving or willing to serve on boards and focus their skills and activity. As the impact of their work is felt and seen by the membership, over time you will find that more volunteers will come forward to participate.

Develop long range goals, such as: (1) identifying policy change areas you cannot currently devote resources to but wish to in the future; (2) developing a library or resource manual for board participation; or (3) increasing the cultural diversity of membership serving on policy-making bodies. Regularly update your member inventory to identify new opportunities for members and to recruit new participants.

Actively inform all of the membership in your organization about the work that is going on at the policy-making level. Have it as an agenda item at all your meetings so that everyone is informed of what is happening, can contribute to problem-solving and ongoing strategy development, and can be reminded of the opportunity and need for their participation. If you have a newsletter, have a regular section that provides brief updates of activity.

By keeping your policy change efforts at the forefront, everyone in the organization will likely come to have some level of investment in its success, regardless of their level of participation.

Support members who serve on policy and decision-making bodies.

As an organization, develop a process for providing board or committee member's consultation, emotional support, and technical assistance in their work. Recognize that such assistance must be individualized to the needs of each member and that there must be an atmosphere that accepts requests for time and help.

Suggestions for Supporting Your Membership

- Identify a "mentor" who has experience working on boards to work closely with new participants, share their experiences, and provide emotional support;
- Hold meetings (or conference calls) at times when policy-making participants can connect with each other to share experiences, coordinate their efforts, and jointly solve problems;
- Develop a mechanism for members to inform the organization of their activities on a regular basis and receive advice and feedback;
- Publicly acknowledge the organization's appreciation for member efforts at meetings, in newsletters or award banquets;
- Pass on any written materials, publications, books or other resources that the organization receives that can help inform them;
- Impress upon policy-making committees the importance and inherent fairness of providing compensation to consumer board members; and
- If reimbursement from committees is not available, set up a small fund to help cover transportation, respite or other costs of participation.

Evaluate Your Efforts

To ensure that both your organization's activities and the individual efforts of your representatives really do make a difference, it is vital that you regularly and formally review your efforts, disappointments and successes. Develop an ongoing process for reviewing your strategic plan and revising it as necessary.

As desired policy or service changes occur, they may spawn a new crop of issues and problems that must be addressed. Unsuccessful efforts on boards, the realization that

member time and energy is not worth the time involved in the board, the need for members to leave boards for personal or other reasons, or even the discovery that a board really can't achieve the changes you desire are just some of the realities you will have to work with.

Schedule regular meetings of your leadership or board of directors to review your strategic plan, reassess your goals, evaluate your successes and areas of concern, and make revisions in the plan as necessary. At the very least, you should do this formally on an annual basis. Better yet, schedule quarterly, or if possible, monthly, time during meetings to update everyone on what is going on. Involve members who are serving on boards and committees in all your evaluation efforts - they are the expert "eyes and ears" for your efforts.

Use every avenue to have the entire membership of the organization involved in evaluation efforts. Regularly informing members at meetings and through newsletters of the progress of your efforts and providing time for feedback and advice will ease these efforts. After your annual, formal review discuss the plan with members at an annual meeting so you receive the full benefit of their experiences, needs and direction.

Seek out the opinions and evaluations of people outside your organization. Talk to or survey professionals about their evaluation of your impact on policy and decision-making change. You may want to have your representatives on boards and committees survey that body to find out how effective you have been, or to obtain suggestions from them on how you could be more effective.

Conclusion

If all this sounds like a lot of work, it is! But ultimately, by organizing and examining your current work, focusing your efforts, and consciously developing a plan of action, the odds of both increasing member participation and seeing real success in policy and service changes will continually build in your favor and to the benefit of all children with emotional disorders and their families.

As advocates and family members, you and your organization are the most skilled and knowledgeable agents for change in your community. As you look to the future, remember the real and fundamental changes, accomplishments, and victories that families

and family organizations have achieved on behalf of their children and themselves. By becoming partners in the policy-making process, parents and other family members can help ensure these changes and victories become long-lasting and permanent.

NOTES

SECTION IV:

RESOURCES FOR DECISION-MAKING

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A minimum of 7.5 million, or at least 12 percent, of the 63 million children in the United States are in need of mental health services for emotional or other problems. Of the 7.5 million estimate, the mental health problems of 3 million of those children (40 percent) are of such degree and persistence that they are identified as "serious" or "severe." Some estimates are even higher, suggesting that possibly as many as 9.5 million children, or 15 percent of America's children, may be in need of mental health treatment.

Approximately 100,000 children and youth (less than one percent of America's children) receive residential treatment center or hospital based mental health services in any given year. Two million children (5 percent) receive outpatient mental health treatment annually. The Office of Technology Assessment, Congress' analytical arm, estimates that 70 to 80 percent of American children in need of mental health treatment may not be receiving appropriate services.

CHARACTERISTICS

The range of children's mental disorders* are categorized in the following broad categories:

Emotional Disorders--These disorders are characterized by their effect on an individual's emotional state. They may be characterized by anxiety (such as separation anxiety, phobias, post-traumatic stress disorder, and avoidant disorder). Other emotional disorders are affective or mood disorders (such as childhood depression or bipolar disorder--formerly called manic/depression);

Behavioral Disorders--These disorders are characterized by disruptive behavior in school, home, and other settings. They include attention-deficit hyperactivity disorder, conduct disorder, and oppositional disorder;

Psychophysiological Disorders--A disturbance of some bodily functioning characterizes these disorders. Eating disorders (such as anorexia nervosa and bulimia), bladder and bowel disorders (enuresis and encopresis), and stereotyped movement disorders (tics) are examples of these illnesses;

Other Disorders--Schizophrenia is characterized by disintegration of personality and loss of contact with the environment (i.e., hallucinations). Adjustment disorder involves a maladaptive response to a stressful event such as depression or anxiety.

Developmental Disorders--Some children with mental, emotional, or behavioral disorders, also have developmental disorders. These disabilities are characterized by disorders in the acquisition of social, language, motor, or cognitive skills.

"The term developmental disability means a severe, chronic disability of a person which

a. is attributable to a mental or physical impairment or combination of mental and physical impairments;
b. is manifested before the person attains age twenty-two;
c. is likely to continue indefinitely;
d. results in substantial functional limitations in three or more of the following areas of major life activity: (1) self-care (2) receptive and expressive language (3) learning (4) mobility (5) self-direction (6) capacity for independent livingness (7) economic sufficiency; and
e. reflects the person's need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are of lifelong or extended duration and are individually planned and coordinated." The Developmental Disabilities Act of 1984, P.L. 98-527, Sec. 102(7).

Developmental disorders (such as mental retardation and autism) are the primary diagnosis for many children. Autism is a pervasive developmental disorder; specific developmental disorders include developmental reading disorder and developmental articulation disorder.

DEFINITIONS/ELIGIBILITY FOR SERVICES

Children and youth with mental, emotional, or behavioral disorders have (among other names) variously been described as having "serious emotional disturbances," "serious behavior disorders," or "mental illnesses." A child's eligibility for receiving particular services hinges upon meeting applicable federal, state, or agency definitions of the population served. These definitions are described below.

A. Child & Adolescent Service System Program

The National Institute of Mental Health launched the Child and Adolescent Service System Program (CASSP) in 1984. This federal program assists states in developing state and community level coordinated mental health, education, health, social welfare, and juvenile justice services for children and youth with mental, emotional, and behavioral disabilities. CASSP uses the following broad definition (which states may alter to fit local needs) to describe youth eligible to receive services:

Age--under either 18 or 21 years of age (depending upon the jurisdiction);

Disability--the lack of ability to perform in the family, in school, and in the community;

Multi-Agency Need--services are required from two or more community services, such as education, mental health, social welfare, juvenile justice, substance abuse, or health;

Mental illness--a mental or emotional disorder

*This list is not exhaustive

diagnosable under the *Diagnostic and Statistical Manual, Third Edition, Revised* (DSM-III-R) or other classification system used by the state must be present;

Duration--the disability must be present for a minimum of one year or must, on the basis of diagnosis, be expected to last more than one year.

B. Education for All Handicapped Children Act

The federal Education for All Handicapped Children Act (Public Law 94-142), enacted in 1975, guarantees that all children, regardless of any disability, are entitled to a free and appropriate education. This Act defines "serious emotional disturbance" as

"a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree, which adversely affects educational performance:

- An inability to learn which cannot be explained by intellectual, sensory, or health factors;
- An inability to build or maintain satisfactory interpersonal relationships with peers and teachers;
- A general pervasive mood of unhappiness or depression; or
- A tendency to develop physical symptoms or fears associated with personal or school problems."

The federal definition includes children with schizophrenia, but excludes children with social maladjustments (unless determined to have an emotional disability). Children with autism are included under another category entitled "other health impaired." Individual state educational agencies have further refined their definitions of serious emotional disabilities.

CAUSES OF DISABILITY

The causes of mental, emotional, and behavioral disorders in children and youth are not clearly known. Most mental health professionals believe that these disorders are due to a combination of biological, psychological, and environmental factors. Biological factors may include an individual's genetic makeup, brain chemistry, brain infections, serious nutritional deficiencies, and substances such as lead. The area of psychological factors may include problems with intelligence, reasoning ability, self-esteem, and motivation. Environmental or social factors related to peer relations, culture, economics, school difficulties, and family problems may also contribute to emotional problems.

SERVICE NEEDS

Children and youth need a range of community-based services. Historically, children have either not received the services they need or have received overly restrictive care (such as placement in mental hospitals). Services for children should be *child-centered* and *family-focused*--the needs of the child and the family should govern the services provided. Services should also be *community-based* and not limited to restrictive institutions.

Systems of care for children and adolescents with mental, emotional, and behavioral disorders must: (1) include a comprehensive array of services to address a child's emotional, social, physical, and educational needs; (2) provide individualized services to meet the unique potential and needs of each child guided by an individualized service plan; (3) provide services within the most normal and least restrictive environment possible; (4) fully include families in planning and service delivery; (5) provide services that are fully integrated with other child-caring agencies and programs; (6) include case management or similar services to coordinate the delivery of multiple services; (7) promote early identification and intervention on behalf of children with emotional problems; (8) offer smooth transitions to the adult service system as youth reach maturity; (9) protect children's rights and promote advocacy efforts on behalf of children; and (10) provide culturally appropriate services and not discriminate in the provision of services on the basis of race, sex, national origin, sexual orientation, physical disability, religion, family composition, or other characteristics.

FAMILY NEEDS

All families need service providers who work collaboratively with them and are respectful of diverse cultural backgrounds and diverse family compositions. The families of children with mental, emotional, and/or behavioral disabilities have additional needs. Families may--among other needs--want the support of other families with similar experiences, assistance in advocating on behalf of their children, respite care, assistance in meeting the special needs of brothers and sisters of children with disabilities, or help in planning their child's transition from youth to adult service systems. The resources listed below may be of assistance in locating necessary services.

RESOURCES

Association for the Care of Children's Health (ACCH)
3615 Wisconsin Avenue, N.W.
Washington, D.C. 20016
(202) 244-1801
(Offers a variety of family support materials including a consumer guide to health insurance options)

Beach Center on Families and Disability
Bureau of Child Research
3111 Haworth Hall
University of Kansas
Lawrence, Kansas 66045
((913) 864-7600
(Offers free *Families and Disability* newsletter)

CASSP Technical Assistance Center
Georgetown University
2233 Wisconsin Ave., NW
Washington, DC 20007
(202) 338-1831
(Provides technical assistance to state and local CASSP programs)

Child & Adolescent Service System Program (CASSP) State Office
(Contact state department of mental health or the National Clearinghouse on Family Support and Children's Mental Health to locate. State or local CASSP programs offer information on local family support activities and on community-based services for children and families)

Children's Defense Fund (CDF)
122 C Street, N.W.
Washington, D.C. 20001
(202) 628-8787
(Offers a monthly newsletter, resource materials including such subjects as special education and child advocacy, information on legislation)

Council for Exceptional Children (CEC)
ERIC Clearinghouse on Handicapped and Gifted Children
1920 Association Drive
Reston, Virginia 22091-1589
(703) 620-3660
(Provides information on education related topics through summary digests, bibliographies, customized computer searches)

Federation of Families for Children's Mental Health
1021 Prince Street
Alexandria, Virginia 22314-2971
(703) 684-7710
(A national parent-run organization focused on the mental health needs of children and youth with emotional, behavioral, or mental disorders; provides assistance in locating local family support groups)

Higher Education and Adult Training for People with Handicaps (HEATH) Resource Center
National Clearinghouse on Postsecondary Education for Individuals with Handicaps
One Dupont Circle, Suite 800
Washington, D.C. 20036-1193
(202) 939-9320
(800) 544-3284
(Offers information on post-high school education and training opportunities, policies, adaptations and services for people with disabilities)

Mental Health Law Project (MHLP)
2021 L Street, N.W., Suite 800
Washington, D.C. 20036
(202) 467-5730
(Pursues litigation, legislation, and policy advocacy on behalf of children and adults with mental or developmental disabilities)

National Alliance for the Mentally Ill Children and Adolescents Network (NAMI CAN)
2101 Wilson Boulevard, Suite 302
Arlington, Virginia 22201
(703) 524-7600
(National organization and local affiliates offer support, information, and advocacy for parents whose children have serious mental or emotional disabilities)

National Association of Protection and Advocacy Systems (NAPAS)
900 Second Street, N.E., Suite 211
Washington, D.C. 20002
(202) 408-9514
(State Protection and Advocacy offices pursue administrative, legal, and other remedies/protections for individuals with mental or physical disabilities)

National Center for Clinical Infant Programs (NCCIP)
733 Fifteenth Street, N.W., Suite 912
Washington, D.C. 20005
(202) 347-0308
(Provides information on infant and early childhood health, mental health, and development)

National Clearinghouse on Family Support and Children's Mental Health
Research and Training Center on Family Support and Children's Mental Health
Portland State University
P.O. Box 751
Portland, Oregon 97207-0751
(800) 628-1696 (Clearinghouse)
(503) 725-4040 (Research and Training Center)
(Offers free *Focal Point* newsletter; information on children's mental, emotional, and behavioral disabilities; technical assistance to family organizations)

National Conference of State Legislatures
1050 Seventeenth Street, Suite 2100
Denver, Colorado 80265
(303) 623-7800
(Publishes *What Legislators Need to Know About Children's Mental Health*)

National Information Center for Children and Youth with Handicaps (NICHCY)
P.O. Box 1492
Washington, D.C. 20013
(800) 999-5599
(703) 893-6061
(Offers fact sheets on available resources, sponsors conferences on matters affecting children with disabilities and their families, maintains a database of articles on emotional disabilities)

National Mental Health Association (NMHA)
1021 Prince Street
Alexandria, Virginia 22314-2971
(703) 684-7722
(National organization and local affiliates provide information, public education, legislative action)

National Rehabilitation Information Center (NARIC)
4407 Eighth Street, N.E.
Washington, D.C. 20017
(202) 635-5826
(800) 34-NARIC
(Offers information on disability-related research, state resource guides, and customized database searches)

Research and Training Center for Children's Mental Health
Florida Mental Health Institute
13301 Bruce B. Downs Boulevard
Tampa, Florida 33612-3899
(Offers free *Update* newsletter)

Sibling Information Network
Department of Educational Psychology
Box U-64
University of Connecticut
Stoors, Connecticut 06268
(203) 486-4034
(Publishes quarterly *Sibling Information Network Newsletter*)

Technical Assistance for Parent Programs (TAPP)
95 Berkeley, Suite 104
Boston, Massachusetts 02116
(617) 482-2915
(Offers information on parent training and information programs)

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ATTENTION DEFICIT HYPERACTIVITY DISORDER

Description/Symptoms/Diagnosis

Attention Deficit Hyperactivity Disorder has also been referred to as hyperactivity or hyperactive disorder, among other terms. It is as a developmental disorder that involves low attention span, impulsivity and/or overactivity in which behaviors are inappropriate for the age of the child. Attention Deficit Hyperactivity Disorder (ADHD) begins in early childhood; the symptoms of the disorder are generally chronic, occur across situations (i.e., at home, at school, with peers). Children who have been diagnosed as having ADHD may experience a number of cognitive, academic, emotional, social and physical problems in addition to their primary disorder. These children may have problems in academic achievement, depression, low self-esteem, and poor peer acceptance.

Some experts believe that the signs of this disorder can be identified in early infancy. Infants with a difficult temperament, who are excessively active, have poor sleeping and eating habits, and are negative in their moods appear to be at greater risk for later ADHD.

Causation/Incidence

Various causes have been proposed for this disorder. Most children's mental health specialists now view the disorder as arising from various sources. A hereditary cause for ADHD has been the focus of recent research. Congenital causes seem to have the greatest support among experts although other factors, such as environmental toxins or allergic reactions to food additives have been suggested. Some children from chaotic or abusive home environments can develop symptoms like those of ADHD.

ADHD is one of the more common disorders seen by child mental health specialists. The number of boys diagnosed with the disorder far outnumber girls.

This disorder tends to be chronic throughout childhood; approximately one-third of children with this disorder will continue to show signs of the disorder in adulthood.

Treatment

The type of treatment proposed for this disorder is one of the most highly debated issues in children's mental health at the current time. Some feel that there is no question but that stimulant medication (Dexedrine, Ritalin, Cylert) is highly effective for school-age children diagnosed with Attention Deficit Hyperactivity Disorder. Others argue that various types of behavior management techniques are just as effective as stimulants and do not produce negative side effects. Others say that behavior and cognitive therapies are more effective than medication. In up to 75 percent of the children with a diagnosis of ADHD, medication reduces the hyperactivity, increases attention span, and decreases incidents of impulsive behavior. (A child with ADHD and a family history of tics is at risk for developing tics if placed on these medications.) However, the best evidence is that medication alone generally has little lasting benefit and may fail to produce desirable changes in academic behavior and peer relationships. For this reason, the most frequently suggested treatment is medication in conjunction with therapies

designed to improve academic skills and interpersonal relationships.

Role of Family/Impact on Family

Life with a child who has a serious emotional disorder may be associated with a number of troubling and conflicting feelings: love, anger, anxiety, grief, guilt, fear, and depression. These feelings are not unusual; most parents find it is helpful to share these feelings with someone else--family, friends, a support group, or some other informal group. Parents need to realize the scope and limitations of their responsibility and learn to take care of themselves as well as their child. Professional help in the form of individual, couples, or family counseling may be helpful in providing emotional support and guidance and help in the child's recovery.

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childhood depression is imperative. Medications, such as antidepressants or lithium, can be an important part of treatment of depression in children and adolescents, just as it is with adults. However, research with children suggests that medications alone may not completely address all the symptoms of the child with depression. Some children also may have problems with social skills and other areas of social functioning and may benefit from other types of treatment such as individual, group, family therapy, or behavioral therapy.

Role of Family/Impact on Family

Life with a child who has a serious emotional disorder may be associated with a number of troubling and conflicting feelings: love, anger, anxiety, grief, guilt, fear, and depression. These feelings are not unusual; most parents find it is helpful to share these feelings with someone else--family, friends, a support group, or some other informal group. Parents need to realize the scope and limitations of their responsibility and learn to take care of themselves as well as their child. Professional help in the form of individual, couples, or family counseling may be helpful in providing emotional support and guidance and help in the child's recovery.

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DEPRESSION IN CHILDHOOD

Description/Symptoms/Diagnosis

Depression is a type of mood disorder with a variety of symptoms that may vary depending on the age of the child. In many ways the disorder is similar to depression in adulthood in that children may look sad, express hopelessness, lose interest in their usual activities, sleep more or less than usual, have a poor appetite, and express a feeling of tiredness. In younger children, however, some of the symptoms may be different. For example, they may cling to their parents, refuse to go to school, or express exaggerated fears of their parents' death. In adolescents, symptoms of depression manifest themselves in yet other ways such as sulkiness, refusal to cooperate in family and social activities, school problems and perhaps abuse of drugs or alcohol. Older children with depression become restless, grouchy, or aggressive.

Depression may occur as a single episode, be recurrent, or accompany a manic episode as in a bipolar disorder (formerly called manic-depressive disorder). Problems in diagnosing depression in childhood are related to developmental stages of "normal" childhood. **It is sometimes difficult to know whether children are just going through a stage of development, such as the "terrible twos" or "turbulent adolescence," or if they truly are depressed.** Episodes of low moods when things go wrong are just as common among children as they are among adults; these are sometimes referred to as "reactive" depressions. Childhood depression may be unrecognized or misdiagnosed when symptoms are mixed with other behaviors such as hyperactivity or delinquency.

Causation/Incidence

Most mental health professionals now agree that depression, including childhood depression, has an organic basis. This means that depression is rooted in a person's chemical makeup which is largely determined by genetics. **Studies show that depression runs extensively through some families and not others.** It is also widely acknowledged that very stressful events can trigger any of the above types of depression. If a person's body chemistry is genetically linked to depression, it may take relatively little to trigger a depressive episode. Tests are being investigated which may show how chemical balance is disrupted during depressive episodes.

Feelings of sadness and increased emotional intensity are common among children and adolescents. However, only 10 to 12 percent of ten-year-olds of these children are severely depressed and have symptoms in need of treatment. Depression increases sharply in adolescence. Some surveys have indicated that symptoms of depression may occur in as many as 40 percent of teenagers. Depressive disorders in childhood are more common among boys whereas in adolescence such disorders are more common among girls. Suicide and substance abuse can be complications of depression. Adolescents attempt or commit suicide far more often than children do. Suicide is rare in children under twelve years of age.

Treatment

Untreated depression may lead to subsequent problems in adulthood. Also because of the possibilities of suicide in adolescence, **early detection and treatment of**

SCHIZOPHRENIA IN CHILDHOOD

Description/Symptoms/Diagnosis

The diagnosis of schizophrenia during childhood is one of the more severe mental disorders. During and before the 1970's it was believed that schizophrenia in children was the same disorder as autistic disorder (formerly autism). Most specialists now distinguish between autistic disorder and schizophrenia in childhood. Schizophrenia in children is not a separate disorder, but is diagnosed in the same way as schizophrenia is in adults. Schizophrenia, in general, refers to a psychotic disorder whereby there is a loss of contact with the environment and a disintegration of the personality. Symptoms include hearing one's thoughts spoken aloud, auditory hallucinations ("voices" that give commands, comment on the person's behavior, etc.), the feeling of having one's thoughts controlled, delusions (fixed false beliefs), and feeling that one can spread thoughts to others.

Children with schizophrenia appear to be enclosed in their own world; they are withdrawn. Childhood schizophrenia is thought to be rare; the onset of schizophrenia usually occurs in late adolescence or young adulthood.

Schizophrenia is often a life-long disorder. Schizophrenia which begins during childhood tends to have a poor prognosis.

Causation/Incidence

Research shows an increase in risk for schizophrenia and schizophrenic-like behavior in those who have relatives with schizophrenia; such evidence strongly suggests a genetic component. Even though it is widely thought that schizophrenia is a genetic disorder, environmental factors may also be involved. Studies of individuals at high risk for schizophrenia have found that neurodevelopmental immaturities, attention deficits, and impaired interpersonal relationships are associated with later onset of schizophrenia.

Treatment

The symptoms of schizophrenia are often treated with medication commonly known as anti-psychotic medication. Treatment should also involve helping the child learn how to live with the cognitive, sensory, and affective deficits that are associated with schizophrenia in children. Treatment planning should be highly individualized and ongoing. A program should begin with the child's current level of functioning and build on the strengths of each child and family.

Role of Family/Impact on Family

Life with a child who has a serious emotional disorder may be associated with a number of troubling and conflicting feelings: love, anger, anxiety, grief, guilt, fear, and depression. These feelings are not unusual; most parents find it is helpful to share these feelings with someone else--family, friends, a support group, or some other informal group. Parents need to realize the scope and limitations of their responsibility and learn to take care of themselves as well as their child.

Professional help in the form of individual, couples, or family counseling may be helpful in providing emotional support and guidance and help in the child's recovery.

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CONDUCT DISORDER

Description/Symptoms/Diagnosis

Conduct disorder is a persistent pattern of conduct in which the basic rights of others and major age-appropriate societal norms or rules are violated. The behaviors must occur over time, not just be isolated antisocial acts. Symptoms begin during childhood or adolescence.

Conduct disorders may be mild, moderate or severe in nature. Mild forms tend to dissipate as a child matures, but more severe forms are often chronic. Conduct disorders appear in many settings, including the home, the school, with peers, and in the community. Children with conduct disorder are often physically aggressive and cruel to other people and animals. They may set fires, steal, mug, or snatch purses. In later adolescence, they may commit more serious crimes such as rape, assault, or armed robbery. These children typically lie and cheat in games and in schoolwork, are often truant and may run away from home. Children with conduct disorder often show no concern for the feelings of others and fail to show remorse or guilt for harm they have inflicted.

A child is labeled conduct disordered if he or she meets specific behavioral criteria. These children project an image of toughness, but usually have low self-esteem. They often have other difficulties as well, such as depression, low problem-solving skills, learning disorders, and problems with substance abuse. A large number of these children are also diagnosed as having attention-deficit/hyperactivity disorder.

Causation/Incidence

There are various factors which may predispose children and youth to the development of conduct disorder. Most believe that it is a complex interaction of numerous biological, interpersonal, and environmental factors. Developmental disorders and mental retardation are commonly found in conjunction with conduct disorder. Social stressors often include difficulties in the home, a parental history of alcohol dependence, and economic factors. The disorder can begin before puberty. Childhood onset is more commonly seen in boys and adolescent onset is seen more commonly in girls. Approximately 9 percent of boys and 2 percent of girls under age 18 are thought to have the disorder. In the United States, conduct disorders are becoming more common for both sexes and are being seen in younger children. Conduct disorders that are severe enough to result in arrests have been increasing in recent years.

Treatment

Just as there are many potential factors which predispose a youngster to the development of conduct disorder, there are also many forms of treatment. Some are directed toward the child (individual therapy, behavioral therapy, training in problem solving), the family (parent management training, family therapy), the peer group (group therapy), and community- based interventions (recreation and youth centers). At present, none of these forms of treatment have had more than limited success. Behavior modification and group counseling have had limited success during treatment, but there is no evidence that they provide long term benefits. Among the family therapies, only functional family therapy (FFT), an integrative approach based on behavioral techniques presented in a family systems context, has had positive outcomes. A goal of FFT is to improve the communication and support of the family. It also appears that a combination of parent management training (PMT) and problem-solving skills training for children has medium range positive effects on behavior.

Role of Family/Impact on Family

Life with a child who has a serious emotional disorder may be associated with a number of troubling and conflicting feelings: love, anger, anxiety, grief, guilt, fear, and depression. These feelings are not unusual; most parents find it is helpful to share these feelings with someone else--family, friends, a support group, or some other informal group. Parents need to realize the scope and limitations of their responsibility and learn to take care of themselves as well as their child. Professional help in the form of individual, couples, or family counseling may be helpful in providing emotional support, guidance, and help in the child's recovery.

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ANOREXIA NERVOSA AND BULIMIA NERVOSA

Description/Symptoms/Diagnosis

Two types of eating disorders commonly affect adolescent girls: anorexia nervosa and bulimia nervosa. Adolescents with anorexia nervosa have an intense fear of obesity and pursue thinness through self-imposed starvation. Individuals with this disorder have a distorted body image and an intense fear of gaining weight. They often experience high levels of guilt and shame in relation to eating. Common signs of anorexia nervosa include: extremely low body weight; the loss of menstruation; excessive exercising; constipation; lowered heart rate, blood pressure and/or body temperature; swelling of feet, hands, nose, and ears; dry skin and brittle nails; hair loss, and bizarre behaviors or thinking patterns, such as a preoccupation with and hoarding of food.

Bulimia nervosa is characterized by episodic binge eating in which large quantities of food are consumed with a sense of urgency or loss of control and subsequent purging in which an individual may vomit, abuse laxatives, diet pills, amphetamines and caffeine, exercise excessively or follow a strict diet to counteract the effects of overeating. Depression and self-critical thoughts may follow a binge. Bulimia nervosa may cause weight fluctuation and overemphasis on eating. Symptoms include: irregular menstrual cycles or the loss of menstruation, muscle weakness or cramping, fatigue, dental problems, gastro-intestinal problems, and intolerance of cold.

Causation/Incidence

Anorexia nervosa and bulimia nervosa have become increasingly common among adolescent and adult women, affecting as much as one to eight percent of the population. Males account for 5-10 percent of cases. The age of onset range for these eating disorders range from 10 to 50 years. Both of these disorders have tended to occur disproportionately among middle and upper class females, but there is some evidence that anorexia nervosa is now also occurring among females of other socio-economic classes.

Both anorexia nervosa and bulimia nervosa are thought to be caused by complex biological, psychological and social factors. The following factors may be associated with these disorders: a history of obesity or being overweight, affective disorders, anxiety disorders, neuroendocrine problems, personality characteristics, previous sexual abuse, and strong cultural norms that idealize thinness and promote unrealistic role models for females.

Treatment

Several kinds of therapies have frequently been used to treat anorexia nervosa and bulimia nervosa. Treatment of malnutrition is a primary goal of all treatment. *Individual Psychodynamic Therapy* focuses on enhancing a patient's self-esteem, correcting her distorted view of her body image, encouraging her to feel independent, and helping her to develop a strong, self-directed identity. Using *behavioral therapy*, patients with anorexia are rewarded for weight gain and patients with bulimia are taught to re-think their ideas about food so that healthy eating patterns are established. *Group therapy* has been used treating individuals with bulimia nervosa. Group therapy emphasizes personal responsibility and assertive behavior to counter feelings of helplessness, helps patients to explore their body images, and provides a safe, supportive environment to work through victimization experiences. *Self-help groups* are often used in along with therapy as is *family therapy*. Psychotropic medication is also often helpful to alleviate some of the symptoms.

Role of Family/Impact on Family

Life with a child who has an emotional disorder may be associated with a number of troubling and conflicting feelings: love, anger, anxiety, grief, guilt, fear, and depression. These feelings are not unusual; most parents find

it is helpful to share these feelings with someone else--family, friends, a support group, or some other informal group. Parents need to realize the scope and limitations of their responsibility and learn to take care of themselves as well as their child. Professional help in the form of individual, couples, or family counseling may be helpful in providing emotional support, guidance, and help in the child's recovery.

References and Resources

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American Anorexia/Bulimia Association, Inc.
425 East 61st Street, 6th Floor
New York, New York 10021
Phone: (212) 891-8686
Provides information and referrals, counseling, self-help groups, speakers bureau, quarterly newsletter, group development assistance, conferences.

National Anorexic Aid Society, Inc.
Harding Hospital
1925 E. Dublin Granville Road
Columbus, Ohio 43229
Phone: (614) 436-1112
Support and education for people suffering from anorexia, bulimia, and related eating disorders. Also for families and friends.

National Association of Anorexia Nervosa & Associated Disorders, Inc.
P.O. Box 7
Highland Park, Illinois 60035
Phone: (708) 831-3438
Provides information on self-help groups and therapy; referrals to professionals.

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FAMILY SUPPORT GROUPS

Support groups composed of family members whose children have serious emotional disorders offer members comfort and reassurance, short term relief from caregiving responsibilities, advice and assistance from families who have had similar experiences, humor, and the opportunity to learn to improve their ability to obtain services for their children.

Different support groups have different goals--some focus on providing personal support while others regularly invite speakers or focus on developing advocacy/lobbying skills. Among other activities, support groups may develop newsletters, build lending libraries of resource materials and books for family members, or develop lists of community resources.

The issues groups may address include: (1) how to find a meeting site; (2) ways to reach families and let them know the group exists; (3) how to fund photocopying, postage, and refreshment expenses; (4) structuring and running meetings; and (5) whether to meet independently or invite professionals to participate. The books and organizations listed below can provide assistance in resolving these and other issues that arise in forming and maintaining a family support group.

Developing and Maintaining Support Groups:

Brownstone, Douglass. *Parents together. A manual for leaders of support groups for parents of children experiencing emotional and behavioral disorders*. Production Services Unit, New York State Office of Mental Health, 44 Holland Avenue, Albany, New York 12229; (518) 474-8394. **(Note specific focus on emotional disabilities.)**

Des Jardins, C. (1980). *How to organize an effective parent/advocacy group and move bureaucracies*. Coordinating Council for Handicapped Children, 407 South Dearborn, Room 680, Chicago, Illinois 60605; (312) 939-3513.

Donner, R., & Fine, G.Z. (1987). *A guide for developing self-help/advocacy groups for parents of children with serious emotional problems*. Georgetown University Child Development Center, Bles Building CG-52, 3800 Reservoir Road, N.W., Washington, D.C. 20007; (202) 687-8635. **(Note specific focus on emotional disabilities.)**

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Lakey, B. *Meeting facilitation: The no magic method*. New Society Publishers, 4722 Baltimore Avenue, Philadelphia, Pennsylvania 19143.

Nathanson, M. (1986). *Organizing and maintaining support groups for parents of children with chronic illness and handicapping conditions*. Association for the Care of Children's Health, 3615 Wisconsin Avenue, N.W., Washington, D.C. 20016; (202) 244-1801.

Norman, L.K. (Ed.). (1988). *National directory of organizations serving parents of children and youth with emotional and behavioral disorders* (2nd ed.). Research and Training Center on Family Support and Children's Mental Health, Portland State University, P.O. Box 751, Portland, Oregon 97207-0751; (503) 725-4040.

Steele, B. & Willard, C. (1983). *Guidelines for establishing a family resource library*. Association for the Care of Children's Health, 3615 Wisconsin Avenue, N.W., Washington, D.C. 20016; (202) 244-1801.

Straw, P. (1982). *Awakenings. Organizing a support/advocacy group*. National Alliance for the Mentally Ill, 2101 Wilson Blvd., Suite 302, Arlington, Virginia 22201; (703) 524-7600.

Parent to Parent National Project Training Package (Videos & Training Manual), University Affiliated/University of Georgia, 850 College Station Road, Athens, Georgia 30610; (404) 542-6629. The training package is also available through each state's mental health division or Developmental Disabilities Council.

Parent Handbooks:

Binkard, B., Goldberg, M., & Goldberg, P.F. (1990). *A guidebook for parents of children with emotional disorders* (2nd ed.). PACER Center, Inc., 4826 Chicago Avenue S., Minneapolis, Minnesota 55417; (612) 827-2966.

Norman, L.K. (Ed.). & Kelker, K.A. (19). *Taking charge: A handbook for parents whose children have emotional handicaps* (2nd ed.). Research and Training Center on Family Support and Children's Mental Health, Portland State University, P.O. Box 751, Portland, Oregon 97207-0751; (503) 725-4040.

National and State Organizations:

Child & Adolescent Service System Program (CASSP) State Office. Call or write the state department of mental health to locate. State or local CASSP programs offer information on local family support activities and on community-based services for children and families.

Federation of Families for Children's Mental Health
1021 Prince Street
Alexandria, Virginia 22314-2971
(703) 684-7710
A national parent-run organization focused on the mental health needs of children with emotional, behavioral, or mental disorders; provides assistance in locating or forming local family support groups.

National Alliance for the Mentally Ill Children and Adolescents Network (NAMI-CAN)
2101 Wilson Boulevard, Suite 302
Arlington, Virginia 22201
(703) 524-7600
National organization and local affiliates offer support, information, and advocacy for parents whose children have serious mental or emotional disabilities.

Technical Assistance for Parent Programs (TAPP)
95 Berkeley, Suite 104
Boston, Massachusetts 02116
(617) 482-2915
Offers information on parent training and information programs.

EARLY INTERVENTION SERVICES

Early intervention services to children with special needs and their families can reduce the social, emotional, cognitive, physical, or language and speech delays that children experience. These services may also reduce family stress. Early intervention services include:

(1) family counseling and home visits;
(2) special instruction;
(3) psychological services;
(4) case management services;
(5) early identification, screening, and assessment services; and
(6) health services necessary to enable a child to benefit from other early intervention services.

Early intervention services are provided by a variety of individuals including special educators, psychologists, social workers, nurses, nutritionists, speech pathologists, audiologists, occupational therapists, and physical therapists. Through Public Law 99-457, the Education of the Handicapped Amendments of 1986, Congress launched an effort to improve services for young children with special needs and their families. These efforts are described below.

A. Required Programs: Preschoolers

Title II of the Act (also called the Preschool Grant Program) *requires* state education agencies to provide a free, appropriate, public education (FAPE) to all three, four, and five year-old children with disabilities by 1990-91. The legislation extends Public Law 94-142, the Education for All Handicapped Children Act of 1975, to preschoolers and entitles them to (among other services): (1) **individualized education programs (IEPs)**; (2) **education in the least restrictive environment**; (3) **due process procedures to ensure fair educational decisionmaking**; and (4) **non-discriminatory testing.**

Three, four, and five year-old children with serious emotional disorders are entitled to receive services under the Preschool Program. In contrast to the services provided for children with disabilities between ages six and eighteen, services may be delivered *both* to children and their parents. In recognition of the central role family members play in the lives of young children, parental instruction is an allowable expense.

B. Optional Programs: Infants and Toddlers

Part H (also called Title I) of the legislation provides funds to states to develop and implement statewide, coordinated, comprehensive, multidisciplinary, interagency programs for all infants and toddlers (birth to age two) with special needs. States may *choose* whether to participate in the handicapped infant and toddler program. Public Law 99-457 defines "handicapped infants and toddlers" as "individuals from birth to age 2, inclusive, who need early intervention services because they: (a) are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more of the following areas: cognitive development, physical development, language and speech development, psychosocial development, or self-help skills, or (b) have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay. Such term may also include, at a State's discretion, individuals from birth to age 2, inclusive, who are at risk of having substantial developmental delays if early intervention services are not provided." Each state must develop its own definition of the term "developmentally delayed" for purposes of determining children's eligibility for services.

Each infant and toddler with special needs and that child's family will receive: (1) an **individualized assessment** of the child and family's unique needs and identification of appropriate services to meet those needs; (2) a written **individualized family service plan (IFSP)** developed by a multidisciplinary team including the child's parent or guardian; and (3) **periodic review** of the IFSP.

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Smith, B.J. (1988). P.L. 99-457. The new law. In Schrag, E., *Sensitivities, skills, and services: Mental health roles in the implementation of Part H of PL 99-457, the Education of the Handicapped Act Amendments of 1986*, pp. 12-15. (National Institute of Mental Health, Rockville, Maryland 20857).

Additional Resources

A Parents' Guide to Accessing Programs for Infants, Toddlers, and Preschoolers with Handicaps. National Information Center for Children and Youth with Handicaps (NICHCY), P.O. Box 1492, Washington, D.C. 20013; (800) 999-5599 (Free).

Exceptional Parent Magazine, Vol. 19, No. 1 (January-February 1989). Entire issue is on early intervention. *Exceptional Parent*, 1170 Commonwealth Avenue, Third Floor, Boston, Massachusetts 02134; (617) 730-5800.

Fox, H.B. & Yoshpe, R. (1987). *Medicaid financing for early intervention services.* National Center for Networking Community Based Services, Georgetown University Child Development Center, 3615 Wisconsin Avenue, N.W., Washington, D.C.; (202) 687-8635.

Governor's Office (The Governor of each state participating in the Infant and Toddler Program has appointed a State Interagency Coordinating Council to coordinate the state's development of early intervention services.)

OSERS News in Print, Vol. 1, No. 4 (Spring 1988). Entire issue is on early intervention. U.S. Department of Education, Washington, D.C. 20202-2524; (202) 732-1241 (free).

Mental Health Law Project (MHLP)
Early Intervention Advocacy Program
2021 L Street, N.W.
Suite 800
Washington, D.C. 20036-4909
(202) 467-5730
(The MHLP is a national public interest organization that advocates on behalf of children and adults with mental disabilities)

National Association of Protection and Advocacy Systems
220 I Street, N.E.
Suite 150
Washington, D.C. 20002
(202) 546-8202

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FINANCING CHILDREN'S MENTAL HEALTH SERVICES

One of the most difficult tasks confronting families whose children have serious emotional disorders is paying for treatment and other necessary services. Expenses frequently exceed the limits of family insurance policies--especially if psychiatric hospitalization, residential treatment, or other out-of-home placement is involved. In addition to personal resources and family insurance coverage, other possible sources of funds to pay for services include: (1) Title IV-E of the Social Security Act (1980); (2) Title V of the Social Security Act (1981); and (3) Medicaid (Title XIX of the Social Security Act; 1965).

Insurance. Families whose children have serious mental, emotional or behavioral disorders have special health insurance needs. Factors to be considered in selecting an appropriate health plan include: (1) enrollment requirements or limitations (such as precluding coverage of pre-existing conditions); (2) cost (premium, deductible, co-payment, lifetime maximum limitations); (3) covered benefits (i.e., are mental health services covered?); and (4) whether the family's current providers participate in the insurance plan.

Title IV-E. Also known as Public Law 96-272, the Adoption Assistance and Child Welfare Act of 1980, this law sets forth the conditions under which states may receive federal dollars for out-of-home placement. Many child welfare personnel *mistakenly* believe that states cannot be reimbursed with federal funds unless legal custody has transferred to the state and therefore require parents or guardians to relinquish legal custody to obtain services. In fact, voluntary placement agreements are permissible. Moreover, a judicial determination that the voluntary placement is in the best interests of the child is required for federal reimbursement *only* where the placement extends beyond 180 days.

Title V. Also known as the Maternal and Child Health Services Block Grant or as state program for Children with Special Health Care Needs (CSHC), this law serves all women fifteen to forty-four years of age and all children from birth to age twenty-one. Title V is an important funding source for early intervention services (screening and intervention programs to identify and help children at risk for emotional problems and their families). Although each state may determine what Title V services it will offer, most Title V state agencies provide initial diagnostic services, as well as case management (coordinating the assessment of needs and provision of services to a child and family; advocating for the child and family) and limited treatment services. Information on applying for the Title V program is available through state health departments or family pediatricians.

Title XIX/Medicaid. Medicaid is a federal program that reimburses states for a proportion of the costs of providing medical care to low income people. Early and periodic screening, diagnosis and treatment services for children (EPSDT) are provided by all state Medicaid programs. Due to recent Congressional changes, states are required to: (1) provide children served under Medicaid with EPSDT screenings when determined to be medically necessary by a qualified professional; and (2) where an EPSDT screening discovers a condition, reimburse related treatment services that are allowed under federal law, even if these services are not offered to other state Medicaid recipients.

Much of the medical care provided with Medicaid funds has been provided in hospitals. Hospital care is both expensive and often not the most appropriate setting to provide services to children with emotional disabilities. States may seek Medicaid waivers for home and community-based care (such as case management services, day treatment, crisis management and emergency services) if the community care is no more expensive than the hospital/institutional care. Mental health advocates are working to change state Medicaid

plans to increase the provision of Medicaid-eligible mental health services to children and youth. Information on applying for Medicaid funding is available through county health, welfare, or social service agencies.

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Fox, H.B. & Yoshpe, R. (1987). *An explanation of Medicaid and its role in financing treatment for severely emotionally disturbed children and adolescents.* Child and Adolescent Service System Program Technical Assistance Center, Georgetown University Child Development Center, 3615 Wisconsin Avenue, N.W., Washington, D.C. 20016; (202) 364-4164.

Koyanagi, C. (1988). *Operation help. A mental health advocate's guide to Medicaid.* National Mental Health Association, 1021 Prince Street, Alexandria, Virginia 22314-2971; (703) 684-7722.

McManus, M.A. (1988). *Understanding your health insurance options: A guide for families who have children with special health care needs.* Association for the Care of Children's Health, 3615 Wisconsin Avenue, N.W., Washington, D.C. 20016; (202) 244-1801.

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Additional Resources

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Family/Professional Collaboration

The Perspective of Those Who Have Tried

EVALUATION FORM

1. Who used the handbook? (Check all that apply.)

   ❑Parent ❑Educator ❑Child Welfare Worker

   ❑Juvenile Justice Worker ❑Mental Health Professional

   ❑Other (Please Specify)_____

2. Please describe the purpose(s) for which you used the handbook:

   _____

   _____

3. Would you recommend use of the handbook to others? (Check one)

   ❑Definitely ❑Maybe ❑Conditionally ❑Under No Circumstances

   Comments:_____

4. Overall, I thought the handbook was: (Check one)

   ❑Excellent ❑Average ❑Poor

   Comments:_____

5. Please offer suggestions for the improvement of subsequent editions of this handbook:

   _____

   _____

   _____

   _____

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